

June 28, 2004

The Honorable Edward J. Markey
U.S. House of Representatives
Washington, DC 20515

The Honorable Chris H. Smith
U.S. House of Representatives
Washington, DC 20515

Dear Mr. Markey and Mr. Smith:

We, the undersigned organizations of the Lifespan Respite Task Force, are writing in strong support of your legislation, ***"The Ronald Reagan Alzheimer's Breakthrough Act" (HR 4595)***, that will serve as a living memorial to former President Ronald Reagan and his family's ten year struggle with Alzheimer's disease. The bill will strengthen the federal commitment to Alzheimer's research, provide support for family caregivers, and create a public education campaign to inform the public about prevention techniques that can maintain their brain as they age.

We are especially supportive of those provisions that will provide critical financial, emotional and social support not only to family caregivers of individuals with Alzheimer's, but family caregivers across the lifespan. Family caregivers currently provide about \$250 billion in continuous unpaid care to their loved ones, including young children, adult children, spouses and aging family members with varying disabilities and chronic health conditions. A significant majority of these family caregivers have given up employment or reduced their employment to provide care, enduring great financial hardship. Many also sustain serious physical and emotional consequences as a result of their caregiving responsibilities and resulting stressors.

These important provisions that we fully support include a significant increase in authorization for the National Family Caregiver Support Program that provides critical information and support to family caregivers of the aging population. We are also especially pleased that the legislation includes the full text of the Senate-passed bill, the Lifespan Respite Care Act (S. 538). Respite has been shown to reduce stress associated with caregiving, improve the health and well-being of the caregiver, and even result in the reduction of much more costly out-of-home placements and nursing home care. Despite the absolute necessity of respite to allow caregivers to continue providing care, it is in critically short supply, inaccessible to families because of restrictive eligibility criteria, or seen as an unaffordable "luxury" when other more immediate expenses are pressing. The Lifespan Respite Care Act would provide a coordinated system of respite care that would dramatically improve access to quality respite for family caregivers regardless of age, disability or Medicaid status.

In addition, the meaningful tax provisions included in the bill would help alleviate some of the financial burden by providing relief for extraordinary expenses that other families may not incur, such as specialized child care for children with disabilities, adult day care, prescription drugs and medical bills, specialized care or therapy, and medical equipment. As members of the Lifespan Respite Task Force, we are especially supportive of any financial assistance that can be provided to help families pay for much needed respite services. In conjunction with the enactment of the

Lifespan Respite Care Act of 2003, the tax credit would help make respite a reality for many more caregivers.

We stand ready to assist you with the passage of this important legislation. If you need more information, please don't hesitate to contact any one of our organizations, or Jill Kagan, National Respite Coalition at 703-256-9578 or by email at jbkagan@aol.com.

Sincerely,

American Association of Homes and Services for
the Aging
American Association for Marriage and Family
Therapy
American Association on Mental Retardation
American Health Care Association
American Psychological Association
Americans for Better Care of the Dying
Association of Maternal and Child Health Programs
Association of University Centers on Disabilities
Child Neurology Society
Easter Seals
Family Friends
Family Voices
Hospice Foundation of America
Last Acts Partnership
National Adult Day Services Association
National Alliance for Caregiving
National Association for Home Care and Hospice
National Association for Councils on Developmental
Disabilities
National Association of Social Workers
National Association of State Directors of Special
Education
National Association of State Head Injury Administrators
National Center for Assisted Living
National Council on the Aging
National Family Caregivers Association
National Hospice and Palliative Care Organization
National Organization for Empowering Caregivers
National Quality Caregiving Coalition
National Rehabilitation Association
National Respite Coalition
Paralyzed Veterans of America
Parents Anonymous, Inc.
Project DOCC – Delivery of Chronic Care
Rosalynn Carter Institute for Caregiving
United Spinal Association
Well Spouse Foundation

State Organizations

Association for Choices in Community Supports and
Employment Services – New Jersey
Alabama Lifespan Respite Resource Network
Community Respite Center, Jackson, MI
Eastern Central Alabama United Cerebral Palsy
Epilepsy Foundation of New Jersey
Family Support Center of New Jersey
Iowa Respite and Crisis Care Coalition
Jewish Federation of Metropolitan Chicago
Maryland Respite Care Coalition
Michigan Chronic Illness Coalition
Michigan Respite Coalition
Oklahoma Respite Resource Network
Pennsylvania State Respite Coalition
Respite and Crisis Care Coalition of Washington State
Respite Care Association of Wisconsin
South Carolina Respite Coalition
State Family Council of Utah
Tennessee Respite Coalition
United Cerebral Palsy of Pennsylvania